



FAQ

Indiana State Department of Health Genomics and Newborn Screening Program FOR FUTURE PARENTS AND GUARDIANS

Q: My nurse said my baby needed a PKU test. Is a PKU test the same as newborn screening?

A: Yes. Some health professionals will use the term PKU test as a synonym for newborn screening. The term PKU test can be misleading. Every state screens for phenylketonuria (PKU), a rare

metabolic disorder, but they also screen for many other conditions. Indiana screens for about 50 conditions through the hearing screen, pulse oximetry and heel stick.

Q: Will the newborn screening blood test hurt my baby?

A: Most babies experience some brief discomfort from the heel stick, but it heals quickly and leaves no scar. The following suggestions may help make the screening experience more comfortable for you and your baby:

1. Breastfeed the baby during the procedure.
2. Hold the baby during the procedure.
3. Make sure the baby is warm and comfortable during the procedure.

Studies show that when mothers or health professionals comfort babies during the heel stick, the babies are less likely to cry.

Q: Why are all babies screened at birth?

A: Most babies are born healthy. However, some infants have serious medical conditions even though they look and act like all newborns. These babies generally come from families with no previous history of a condition. Newborn screening allows health professionals to identify and treat certain conditions early. When babies with these conditions are identified at birth they can be treated early and are able to grow up healthy with normal development.

Q: Do parents have to ask for screening?

A: No, it is a normal procedure to screen every baby regardless of whether the parent asks for it and whether the parents have health insurance. The newborn screening information is normally included in the forms for standard medical procedures that the newborn gets after birth. You will sign this form upon arrival at the hospital for the birth of your baby or shortly after. Indiana requires screening to be performed, but does allow parents to refuse for religious purposes. Discuss the decision to decline or refuse testing with a health professional first since newborn screening is designed to protect the baby's health.



Q: How are screening costs covered?

A: Newborn screening in Indiana costs \$100. Most hospitals, birth centers and midwives collect a fee for screening, but health insurance or other programs often cover all or part of the cost. Babies will receive newborn screening regardless of health insurance status.

Q: What is the birth defects registry?

A: The Indiana Birth Defects and Problems Registry, or IBDPR, is the Indiana specific system for babies born with birth defects. The IBDPR looks to promote fetal, infant and child health. The purpose behind IBDPR is to prevent childhood development disabilities, enhance the quality of life of affected children and their families, and reduce infant mortality. After a condition is diagnosed at birth, follow-up and referral to care can be provided.



Q: What is done with my baby's information and mine?

A: The Genomics and Newborn Screening program offers follow-up and wraparound services and work to promote, protect and improve the health of Hoosier babies with genetic conditions and birth defects. You can choose to store your newborns dried blood spot (DBS) from the heel stick for up to three years. Storing the DBS allows you to request it at any time for further screenings, paternity tests, help to locate a missing child and more. The DBS is destroyed after three months if you don't chose to store it.

For more information visit www.NBS.in.gov

